

12-1-2002

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Recommended Citation

Kawamoto, K. (2002). Health Information Online Abundant and Varied. *Interface: The Journal of Education, Community and Values* 2(10). Available <http://bcis.pacificu.edu/journal/2002/10/kawamoto.php>

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Health Information Online Abundant and Varied

Posted on **December 1, 2002** by **Editor**



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About the Author

A young man finds out he has diabetes. A middle-aged woman is diagnosed with breast cancer. A mother suspects her child may have autism. A group of adult children is caring for a parent with Alzheimer's Disease. A college student is struggling with issues of sexual identity. Today all of these people can join millions of others who turn to the Internet for information that can help them better understand and deal with a wide range of health issues that impact them and those they care about.

The phenomenon of ordinary people using the Internet to get health information is relatively recent but growing rapidly, part of a larger development called "health informatics." One pollster estimates that 110 million adults – or 80 percent of adults online – sometimes look for health information on the Internet. The Harris Poll has been studying what it calls "cyberchondriacs" (which is not meant to be a pejorative term), and results from a telephone survey (n=707) in March 2002 reveal that the number of cyberchondriacs has been growing steadily in recent years: 54 million in 1998, 69 million in 1999, and 97 million in 2001 [1].

Likewise, the amount of health information online has been growing as well and takes many different forms. One form could be a Web site devoted to news articles about a wide range of health issues, such as WebMD [2], which is a comprehensive health-related Web site with current and archived news; medical information about particular diseases, drugs and research; electronic discussion groups; a question-and-answer section; a personal health profile service; and more. Sponsored links, which are clearly marked, are paid for by businesses in the health field and help generate revenues for the Web site.

Many news organizations have Web sites with a special link just for health-related news. This is

one way for people to keep current on the latest developments in the health field. Search engines on these sites make it easy to research specific health topics of general interest such as obesity, aging, and recent breakthroughs in drug therapy. For more unusual information – a rare disease, for example, that only a small number of people may be interested in – a more extensive database of articles might be needed. The largest online medical library in the world is the National Library of Medicine [3]. It is the creator of MEDLINE/PubMed, MEDLINEplus, and NLM Gateway. Unlike WebMD, MEDLINEplus has no advertising and, as stated on its Web site, contains “extensive information from the National Institutes of Health and other trusted sources on over 500 diseases and conditions. There are also lists of hospitals and physicians, a medical encyclopedia and dictionaries, health information in Spanish, extensive information on prescription and nonprescription drugs, health information from the media, and links to thousands of clinical trials.” [4] These databases are also useful when a large number of articles from many different sources are needed.

Many national organizations created to help people with a specific disease (or family of related diseases) also sponsor their own informational Web sites. One example is the American Diabetes Association (ADA), which contains a massive amount of information on this one disease [5]. Dozens of others exist. Probably the best way to find these sites is to type in the name of the organization (e.g., Muscular Dystrophy Association or American Cancer Society) or even just the disease or medical/psychiatric condition (e.g., breast cancer, arthritis, irritable bowel syndrome, posttraumatic stress disorder, hepatitis, etc.) in a search engine like Google and review the results. Somewhere high on the list of results should be the national organization’s Web site along with a list of other potentially useful sites. Of course on this list may be less useful sites as well, and the onus of critical evaluation for accuracy and credibility rests with the modern-day “lay medical researcher.” It is one of the tradeoffs for having quick and easy access to such massive and varied amounts of health information.

There are many other sources of health information on the Internet, some of them unconventional. University medical centers or health-related programs often have Web sites devoted to a wide range of health concerns, especially those of interest to college-age students. Columbia University started a rather innovative question-and-answer service for its students in 1993 called, “Go Ask Alice,” which was accessible via the university’s Web site [6]. Students could ask “Alice” a question anonymously, and “she” would respond online. “Alice” was not actually any one person but simply the nominal interface between the public and the university’s health specialists. The question would be routed to and answered by the most appropriate specialist through the online persona of “Alice,” a rather clever educational device because the name sounds friendly and non-judgmental, like the name of favorite aunt or next-door neighbor.

The service proved enormously popular and was expanded beyond the campus community. Questioners – mostly young people – could anonymously ask “Alice” all kinds of things that they might otherwise be too embarrassed or inhibited to ask a real person face-to-face. Not surprisingly, many (but not all) of the questions deal with sex or the typical existential angst of early adulthood. “Alice” tends to answer them in a straightforward, sometimes even humorous,

but medically sound manner, and her readers seem to appreciate that approach. All questions and answers have been archived and organized by topic for anyone to read at their leisure. By reviewing the archives, new visitors to the site may find that the question they had in mind was already answered in the past and even feel relieved that they are not the only ones with such a peculiar concern. Other universities have attempted similar services.

Electronic discussion groups revolving around a medical condition have been helpful to people who either have a disease or know someone with the disease. For many people, this is a useful way of sharing relevant information and experiences; for others, these groups are a way of just venting and finding support among people who can relate to the situation. Participants might talk about different or new therapies, experiences with health care professionals, relationships with family members and loved ones, sadness, depression, hope, pain – whatever comes to mind. Just the opportunity to talk with others online who have gone through (or are going through) the same predicament seems to have therapeutic value for many of these online discussants. Research has shown that caring relationships form even among people who have never met in person. Learning that one has a serious, chronic or terminal illness can give rise to all kinds of conflicting and confusing emotions. Whether online or off, finding a community of people who can relate to this distress in one's life often brings a sense of relief and camaraderie.

These are just a handful of ways that ordinary people are accessing health information through their computers at home, school, work, the library and other places. There are many other examples, such as online academic journals, personal Web sites created by someone interested in a particular health topic, and educational materials designed for specialists but accessible by non-specialists as well. The familiar caveats apply: Online health information is not necessarily accurate. The Internet is not a substitute for professional medical care. Personal information on the Internet will not always be treated confidentially.

Critics worry that non-professionals may be misled by wrong information on the Internet. There has been a long-standing debate in the medical community, for example, regarding the value of so-called alternative therapies. No doubt the potential for charlatanism and exploitation does exist on the Internet, and people in dire straits are often vulnerable to predatory behavior. Nevertheless, health information on the Internet is here to stay and can be a valuable asset to those who use the information judiciously as part of larger wellness program. In fact, a Harris Poll study found that 38 percent of the U.S. respondents said they actually discussed information with their doctors as a direct result of something they saw on the Internet [7].

As long as the caveats are observed, health informatics seems like a powerful tool for self-empowerment. Growing numbers of people are taking the initiative to be responsible for learning about their own health and not simply relying on the explanations and recommendations of busy medical professionals. Vigorous self-education should not be viewed as a threat to professional medical advice but, on the contrary, a positive sign of a motivated patient or family member eager to make informed decisions about the best course of action. Ideally, these decisions should be made in close collaboration with trusted health care providers.

The examples of information-seeking discussed in this article are just a subset of health informatics. The field is much broader than this and involves other ways of combining information technology and healthcare. Medical professionals practice health informatics when they use information technologies among themselves in the service of patient care. Continuing education via the Internet aimed at doctors, nurses, technologists and other medical professionals also falls under the rubric of health informatics. Students doing research on health-related issues using the Internet are benefiting from health informatics.

The conceptual and applied aspects of health informatics, medical informatics and biomedical informatics are gradually being integrated into the academic curricula at major centers of learning. At least two-dozen schools in the U.S. have specialized programs in health or medical informatics, although their curricula may vary depending on their respective areas of emphasis. To name a few examples: The University of Washington has a Division of Biomedical and Health Informatics; Harvard Medical School has a Center for Clinical Computing; and UC San Francisco has a Biological and Medical Informatics Graduate Program. A Web site called Health Informatics Worldwide hosts a remarkable database of health informatics programs around the world, including in the U.S. [8]. Most of these programs are geared to medical professionals.

An increasing number of Web sites serve as the intersection between health professionals and the general public, including members of the news media. The International Longevity Center-USA, which is affiliated with the Mount Sinai School of Medicine, has a Web site devoted to issues of longevity and population aging [9]. Although based on first-rate medical expertise and research, the information contained on the site is easily accessible to non-experts. The content on the ILC-USA's Web site is particularly important as people in societies around the world live longer and governments attempt to address the many facets of this phenomenon through policy-formation and planning.

Another Web site, the Dart Center for Journalism and Trauma, provides information to journalists about the effects of emotional trauma on the victims of crime, tragedies and natural disasters, as well as on the journalists themselves who often have to cover these events [10]. The content on the Web site is based on social science or medical research but is designed specifically for non-experts.

By involving journalists in the information-sharing process, organizations like the ILC-USA and Dart Center are helping to move issues from scientific circles into policy-making circles and the larger public arena. The news media, after all, can play a significant role in helping to focus the public's attention on the important issues of the day.

The field of health informatics is a logical outgrowth of advances in information and medical technology, library studies (sometimes called library and information sciences), and the global information infrastructure. It benefits the specialist and layperson alike and has just begun to hint at its full potential as a vehicle for self-care, civic engagement, continuing medical education, peer support networking, and lifelong learning.

This first column has been an overview of health informatics and has tried to convey that health information on the Internet is not only abundant and varied but is facilitating a paradigm shift in traditional approaches to healthcare and self-care. For years now there has been a movement toward taking more responsibility for one's health, a process that requires a variety of tools for self-directed health education, and health informatics stands at the intersection between that movement and the vast reservoirs of health information that were not always accessible to the non-expert. Future columns will continue to look at the manifestations of health informatics in contemporary society.

At its core, health informatics is really about information literacy. An appropriate way of ending this column, then, is to re-print an excerpt from a statement on information literacy by the Association of College and Research Libraries (ACRL). It suggests what an "information literate individual" should be able to do and provides a good foundation for embarking on a lifelong journey on self-directed health education: [11]

Information literacy forms the basis for lifelong learning. It is common to all disciplines, to all learning environments, and to all levels of education. It enables learners to master content and extend their investigations, become more self-directed, and assume greater control over their own learning. An information literate individual is able to:

- *Determine the extent of information needed*
- *Access the needed information effectively and efficiently*
- *Evaluate information and its sources critically*
- *Incorporate selected information into one's knowledge base*
- *Use information effectively to accomplish a specific purpose*
- *Understand the economic, legal, and social issues surrounding the use of information, and access and use information ethically and legally*

ENDNOTES

[1] See Harris Interactive, "Cyberchondriacs Update," May 1, 2002.http://www.harrisinteractive.com/harris_poll/index.asp?PID=299.

[2] See <http://www.webmd.com>.

[3] See <http://www.nlm.nih.gov>.

[4] See <http://medlineplus.gov>.

[5] See <http://www.diabetes.org>.

[6] See <http://www.goaskalice.columbia.edu>.

[7] See Harris Poll, Health Care News, Volume 2, Issue 12, p. 2.

[8] See <http://hiww.org>.

[9] See <http://www.ilcusa.org>.

[10] See <http://www.dartcenter.org>.

[11] See <http://www.ala.org/acrl/ilintro.html>.

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3 THOUGHTS ON "HEALTH INFORMATION ONLINE ABUNDANT AND VARIED"

Tracie Pressler

on **January 30, 2014 at 6:17 PM** said:

Attractive element of content. I simply stumbled upon your blog and in accession capital to say that I acquire actually enjoyed account your blog posts. Any way I

plotka

on **February 1, 2014 at 1:57 AM** said:

I am a student and i found your info over a internet site very fascinating for my study, Please retain it up.

Zielona Góra

on **February 1, 2014 at 3:38 AM** said:

I and also my buddies came searching at the great tips located on a internet site and just before lengthy I had a terrible feeling I in no way thanked the net internet site owner for people tips. All the individuals are definitely warmed to study them and have now genuinely been generating the most of these things. Several thanks for definitely becoming very type in addition to for figuring out specific really beneficial themes most individuals are really needing being aware of. My sincere apologies for not expressing

appreciation to earlier.